

RIPPLES OF LIFE

Primary Health Care and Family Medicine in the work of an Urban Health Centre

**Gillian Paterson, Sara Bhattacharji, Sushil John,
Guru Nagarajan
with
Reena George and Anna Tharyan**



**This publication is based on the work of the
Low Cost Effective Care Unit
Christian Medical College,
Vellore, Tamil Nadu, India**

COMMUNITY HEALTH CELL

Library and Information Centre

No. 367, Srinivasa Nilaya, Jakkasandra,
I Main, I Block, Koramangala, Bangalore - 560 034.

THIS BOOK MUST BE RETURNED BY
THE DATE LAST STAMPED

--	--	--

RIPPLES OF LIFE

Primary Health Care and Family Medicine
in the work of an urban health centre

Gillian Paterson, Sara Bhattacharji, Sushil John,
Guru Nagarajan

with
Reena George and Anna Tharyan

'It is not just the causes of disease and death that need to be addressed: it is also major questions about what constitutes health and enhances life. New visions of what is possible demand approaches to health care that are flexible, responsive, people-centred, and based on new patterns of collaboration, networking and leadership. In the light of these challenges, LCECU today has developed its distinctive vision, its philosophy, and a way of working that chimes with the forces of life that exist within the community'.

Extract from the introduction

This publication is based on the work of the
Low Cost Effective Care Unit,
Christian Medical College,
Vellore, Tamil Nadu, India.

RIPPLES OF LIFE

Primary Health Care and Family Medicine
in the work of an urban health centre

Gillian Paterson, Sara Bhattachari, Susheel John
Guru Nagarajan

with
Reena George and Anna Tharyan

It is not just the causes of disease and death that need to be addressed. It is also major questions about what constitutes health and enhances life. New visions of what is possible demand approaches to health care that are flexible, responsive, people-centred and based on new patterns of collaboration, networking and leadership. In the light of these challenges, LCECU today has developed its distinctive vision, its philosophy, and a way of working that chooses with the forces of life that exist within the community.

Extract from the introduction

This publication is based on the work of the

Low Cost Effective Care Unit,

Christian Medical College,

Vellore, Tamil Nadu, India.

PHC-100

11289

RIPPLES OF LIFE

Primary Health Care and Family Medicine in the work of an urban health centre

CONTENTS

THANKS	4
---------------	----------

PART ONE: Engaging with Life

Ripples from the past	6
1.1 An invitation to a journey	9
1.2 PHC: An institutional and philosophical crisis	11
1.3 An urban context	14
1.4 Moving the horizons	18
1.5 Family medicine in an urban health centre	21

PART TWO: Case Studies

2.1 Volunteers: The eyes and ears	27
2.2 Murugan: Seeing things differently	35
2.3 Mari: The challenge of community-based psychiatry	41
2.4 Binila: Chronic illness in a woman's world	47
2.5 Arun Kumar: A hopeless case?	53
2.6 Lakshmi: Stigma and healing	61
2.7 Velu: When poor people need hi-tech medicine	67
2.8 Ranjit: Death in the community	71
2.9 Ranjit: Ripples of life	75

PART THREE: The Centrality of Life	79
---	-----------

THANKS

Ripples of Life, and the booklet of case studies in Tamil that accompanies it, are part of the celebrations for the Silver Jubilee of the Low Cost Effective Care Unit in December 2008. The aim of these publications is to give an account of our work that is accessible, dynamic, and contributes effectively to current debates about primary health care and the role of family medicine.

Together, these volumes have been a remarkable collaborative effort involving many people. We are deeply indebted to Dr. Gillian Paterson, who gave unstintingly of her time and herself to turn this dream into a reality. For this, as for so many other things, I want to express my thanks to Dr. Sushil John and Mr. Guru Nagarajan. Without their help, care and interest these publications could not have happened.

Doctors and nurses, technicians and pharmacists, social workers, sweepers and clerical staff have all shared their ideas and passion with the writers. Our heartfelt thanks go also to our partners from the town, Mr. Chandrashekar of the Udavum Ullangal, Mr. Ruby Nakka of the Hope Home, Mr Peter from Uthiramatha Middle School, Mr. Durai and Mr. Kumar and their families who provide lunch for our patients. Our volunteers, or 'local educators', are the backbone of our work in the outreach areas. We have learned so much from Mary, Suryakala, Maryamma, Ruth Puspha, Ruckmani, Neelavathy and Ajji, whose cheerfulness, commitment and eagerness to learn have been an inspiration to all of us.

Dr. Reena George and Dr. Anna Tharyan are both valued partners in our work. Both of them appear in these stories, and have

contributed in other ways to this book. The group that critically reviewed the case studies included the Reverend A C Oommen, who is former chaplain of CMC, Reverend Aruldas, Dr. Jacob K John, Rev. John Lunn and Dr. Suranjan Bhattacharji. My warm thanks to them for their interest and enthusiasm. Isobel Swamidasan read and reread the manuscript at short notice and gave many valuable suggestions and to her I am deeply grateful.

This project would not have been possible without the financial support of Friends of Vellore UK and the Vellore Board USA. Now, as on so many occasions, we thank these generous and faithful friends for their participation in our work.

Mr. Nethaji and the staff of Himalaya Offset Printers have been so very helpful and patient with us. Without their hard work and co-operation this publication would not have been ready in time.

Last, but by no means least, we thank our patients and the community that we serve for giving us permission to share their stories. For all that they teach us, we are deeply in their debt. I have been touched and healed by their grit and quiet courage in the midst of overwhelming odds, by their determination to make things better for their families, their communities and themselves, and by their openness and generosity of spirit. I salute them and many others like them who hallow our portals and give us the opportunity to grow together as brothers and sisters in one human community.

Sara Bhattacharji
December 2008

Ripples from the past

It was 1 January, 1900 when the young, newly qualified Dr Ida Scudder arrived in Vellore and moved into her father's bungalow on the Arni Road. Fired by the determination to serve the women of India, she had completed her medical training, and now here she was, ready to start work alongside her physician father. The story of her call to this work, and of the difficulties and joys of those early days, have become part of the mythology of mission, and of the history of CMC. That story is told, movingly, in Dorothy Clark Wilson's biography, Aunt Ida.

Soon, the Arni Road premises became inadequate, and a mother and child hospital was set up in the town. When this became overcrowded the main hospital moved to its present site, where it continued to grow rapidly. It is of historical and symbolic interest that 'Scudder Ward', founded in 1982, now stands on the very spot of the mother and child hospital where CMC's founder first began to shape her vision, that has, for over a century, been part of the multi-faceted vision and mission of CMC, Vellore.

Part One

ENGAGING WITH LIFE



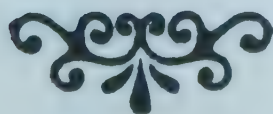
If you have come to help me, then you are wasting your time.

But if you have come because your liberation is bound up with mine, then, let us work together.

Lilla Watson

We must be the change we want to see in the world

M.K.Gandhi





It helps now and then to step back and take the long view.
The Kingdom of God is not only beyond our efforts, it is even
beyond our vision.

We accomplish in our lifetime only a tiny fraction of the
magnificent enterprise that is God's work.
Nothing we do is complete, which is another way of saying that the
kingdom always lies beyond us.
No statement says all that could be said.
No prayers fully express our faith.
No confession brings perfection.
No pastoral visit brings wholeness.
No programme accomplishes the Church's mission.
No set of goals and objectives includes everything.

This is what we are about.
We plant the seeds that one day will grow.
We water seeds already planted, knowing that they hold future
promise.
We lay foundations that will need further development.
We provide yeast that produces effects far beyond our capabilities.
We cannot do everything, and there is a sense of liberation in
realising that.
This enables us to do something, and to do it very well.
It may be incomplete, but it is a beginning, as step along the way.
An opportunity for God's grace to enter and do the rest.
We may never see the end results, but that is the difference between
the master builder and the worker.
We are workers, not master builders; ministers,
not messiahs.
We are prophets of a future not our own.

Oscar Romero
Archbishop of San Salvador



1.1 An invitation to a journey

This book is based on the work of a 40-bedded hospital, located in the urban slum areas that lie at the heart of the South Indian city of Vellore, and dedicated to the health needs of the shifting, impoverished population that calls these areas ‘home’. ‘Scudder Ward’, as it is known locally, is the urban Low Cost Effective Care Unit (LCECU) of the Christian Medical College, Vellore, and as such it is fortunate enough to be structurally part of a large, multi-faceted institution which is able to resource and support its services and activities. Twenty-five years old, it is philosophically located within the story of the primary health movement, and committed to exploring and expanding on the renewed understandings of primary health care that are being developed nationally and internationally. Scudder Ward has a strong commitment to outreach, within the framework of what has come to be known as ‘family medicine’. In responding to the health needs of the community, its staff believe passionately in the importance of a genuine, personal engagement in the realities of people’s lives, and the priority of exposing young trainee health professionals to those realities.

In *Ripples of Life*, we are inviting you to visit these urban streets, to meet some of the people who live here and to enter into the lives of the population we seek to serve. “Share their stories,” we are saying, “and identify, for a time, with their hopes and their fears, their woes and their dreams. Share the process of thinking through some of the issues this work presents”. It is our hope that, in meeting the men, women and children who appear in these pages, you the reader will gain a greater understanding of what it is like to be born and grow up and live and work and die in this context,

and what it means to try - with limited resources within the community and also the centre - to address the health needs of these struggling families and communities. Especially, we want to share with you a particular vision of our work that focuses not on disease but on health, not on death and its causes, but on life.

In entering into this context, and identifying with the case studies which make up the bulk of this publication, the reader will be helped by having some familiarity with the background of the unit, and also with the local context in which we work. In this introduction, therefore, we provide a brief overview of the philosophical and institutional history which lies behind the LCECU we know today. We also attempt to communicate the contextual realities we and our patients live with. However, the approaches to family medicine we are seeking to develop are best understood through the real-life stories and grassroots experience of the individuals and families who feature in the case studies that follow. In these case studies, we have changed some of the names to protect identities, but apart from that we have tried, as far as we are able, to remain faithful to what happened, the context in which these lives are lived, and the responses of the staff. Each story is followed by a set of questions that encourage readers to explore the issues that arise in the context of a people-centred urban family medicine programme, in the first decades of the 21st century. What, we ask, is distinctively *urban* about the problems, the opportunities or the responses that are described? What, for an urban hospital, are the organizational implications of this way of working? What philosophical or ethical challenges do we encounter in our work? What are the particular rewards of this kind of exposure, both for those already engaged in it, and for trainee doctors, nurses and

allied health professionals? And other questions which will certainly occur to you in reflecting on these stories.

We invite you, therefore, to join us in meeting the people we work with and the health problems they encounter - simply, sometimes, in keeping themselves and their families alive. We are happy to share with you our own efforts to develop appropriate and life-promoting solutions to these problems, and to give strength and momentum to the ripples of life that flow within our communities.

1.2 PHC: An institutional and philosophical crisis

In 1978, five years before ‘Scudder Ward’ was born, the World Health Organization held a conference, at Alma Ata in the former Soviet Union, which proved to be a landmark in the history of health care in our times. The Alma Ata Declaration, supported by all member nations, identified primary health care (PHC) as the ground plan for health care in the developing world for the remainder of the 20th century. ‘Health for all by the year 2000’ was the objective of this movement, defining health according to the WHO definition of ‘a complete state of physical, mental and social well-being, not just the absence of disease and infirmity’. Alma Ata set out a way of achieving this end through the dedication of all government services to a bottom up, people-centred approach that empowered individuals, families and communities to take control of their own lives, set their own health priorities, plan health care programmes that were most appropriate for their own contexts, and not just be passive recipients of services.

Then as now, CMC prided itself (and was much valued nationally) as a centre of excellence with a strong commitment to specialist, curative care: but it also had two rural hospitals, CHAD and

RUHSA¹, which served adjacent rural development blocks. Both aspects of the work were important; both contributed to the all-round excellence of its medical education, and also its historic commitment to caring for the poor people in its own area. Accordingly, CMC announced to its supporters that it intended to adopt a ‘both-and’ approach - maintaining and expanding its focus on tertiary medicine while continuing to develop the community health work along PHC principles. With the global debate becoming, at the time, increasingly polarised, this was a brave decision; one that put CMC - for a decade - at loggerheads with many of its funders.

It is important to note that PHC-thinking was then based largely on work in rural contexts, where the huge majority of community-based health programmes were located. But Vellore was a rapidly growing town, with an impoverished population, on the confluence of a number of transport routes. What was needed (in addition to the rural programmes) was a totally new concept, namely a small ‘mission hospital’, within the growing tertiary hospital, which would provide accessible, affordable care to the urban public of Vellore. This centre would be adequate for most of the health needs of poor local people, and should take into account the socio-economic realities of their lives.

The result of this thinking was Scudder Ward, the Low Cost Effective Care Unit, located in the heart of the main hospital, called after CMC’s founder and inaugurated on her birthday, December 9th 1982. The arrangement had many advantages. It would enable the hospital to remain ‘grounded’ in the local population, even as

1. Community Health and Development, and the Rural Unit for Health and Social Affairs

it continued to develop as an international centre of excellence. For staff and trainees, mainly hospital-based and working at the tertiary level, it would provide a way of promoting awareness of the conditions that existed outside the hospital gates, from which many of their patients came. It was also an affirmation of CMC's commitment to its founding principle, which was that it was there in order to meet the needs of the poorest people. In effect, the unit's 'mission' was to provide high-quality, effective care, at minimal cost, with the ready availability of consultant opinions, to the poor of Vellore Town and its surrounding areas.

The story of the primary health care movement has received much attention during the build-up to 2008, which saw the 30th anniversary of the Alma Ata Declaration. In the process, there have been many attempts to analyse the factors that prevented the declaration's vision from being fully realised. There has also been a growing feeling that health strategists need to revisit Alma Ata, see what has been learned during the intervening years, and reclaim its vision for the new world of the 21st century. Under the title *Primary Health Care: Now More Than Ever*, WHO's World Health Report 2008² set out a framework for a reconceptualisation of PHC as a people-centred movement that is oriented towards a genuine engagement with families and communities, responds to their felt needs, and encourages them to build on the strengths and the leadership capacity that exists already within them. It is backed up by the report of the International Commission on the Social Determinants of Health, *Closing the gap in a generation: health equity through action on the social determinants of health*.³

2. Geneva, World Health Organization 2008. www.who.int/whr/current/en/-25k

3. Geneva, World Health Organization 2008

whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf

This renewed interest in PHC is precisely the territory that LCECU has found itself exploring, in the build-up to its own 25th anniversary. Historically, the unit was rooted in PHC thinking, and shaped by the way in which this thinking intersected with CMC's own story. But the world has moved on since 1978. It has been widely realised that models of response designed for rural areas do not transplant readily to urban ones. In towns and cities, living and working environments create new layers of health challenge, with diseases of underdevelopment co-existing with diseases of development. The patterns of illness, the challenges of nutrition, the organization of family life and the strategies needed for survival are different. In this entrepreneurial, media-savvy atmosphere, young urban people are exposed to more complex aspirations and temptations than their rural peers. There are different areas of vulnerability, and the capacity of communities to deal with their vulnerable members may bear little relation to what is encountered in village life.

In this environment, it is not just the causes of disease and death that need to be addressed: it is also major questions about what constitutes health and enhances life. New visions of what is possible demand approaches to health care that are flexible, responsive, people-centred, and based on new patterns of collaboration, networking and leadership. In the light of these challenges, LCECU today has developed its distinctive vision, its philosophy, and a way of working that chimes with the forces of life that exist within the community.

1.3 An urban context

Vellore, in Tamil Nadu, is a city of 200,000 people, situated on the main road and railway route between Chennai and Bangalore.

Much of the centre of Vellore Town is taken up by cluttered slum areas of houses, lean-to's and palm shacks, all huddled together and crisscrossed by incomprehensible systems of red-mud lanes and narrow concrete alleyways. Most of this is unofficial housing, built mainly on *porambokku* land⁴, belonging officially either to the City, or to a local temple, who could at any time reclaim it. In that case these vibrant, ramshackle, impoverished communities could disappear overnight. Around 7000 people live in the Old Town slum and space is at a premium. Where there was once a three-foot gap on a disused balcony or between houses, this has been roofed over with thatch, plastic sheeting, corrugated iron, or whatever came to hand; and now it is somebody's home.

In the daytime, there are always people around: men sawing wood, mending bicycle tyres or managing small stores; women crouched in dark alleyways with their sewing machines, or sitting around their cooking fires preparing the next meal. The elderly are largely hidden away in the dark interiors, but small children are everywhere, many of them half-naked. Even on school days, you will find young boys fooling around in the streets, or chatting noisily on corners. The narrow concrete lanes are shared by streetwise dogs, rubbish-eating goats and donkeys and cows, or pigs that are either rooting for food in the open drains or scampering around in squealing families, guarded by hostile and protective mothers.

Many houses now have electricity. But the 'big event' is the weekly two hour slot when the water is turned on. "The water has come!" somebody shouts: an event which is a source of joy, but also a flashpoint for fights, as a scarce but longed-for commodity becomes

4. Property where the people have settled without registration of land

suddenly but briefly available. The impression, though, is of the whole community flocking to the pumps, their coloured plastic water pots making the streets look festive, while cheerful women take advantage of the occasion by squatting by the roadside washing the family's clothes.

The team at LCECU is led by Dr Sara Bhattacharji. “We are a small hospital,” says Dr Sara, “in an urban area surrounded by slums. Our founding ‘idea’, if you like, was that we should promote health and provide health care for poor people who are not able (for a whole host of reasons) to access the services that are available elsewhere. What, we asked ourselves, is our responsibility to the people around us?”

First, she says, the team looked at the situation of the people. Open drains run along the streets. There is no internal sanitation, but particular areas of open space are designated for defecation purposes, with men and women going at different times. Water is carried in huge pots, normally by women or children: but water, for much of the year, is available only for two hours once a week; or in the summer, only once every fifteen days. A needs assessment survey in two slums of Vellore Town found that access to safe water supply, sanitation facilities, and garbage disposal was very low.

Economic situations are equally fragile. The people in this area are mostly employed in physical work. This may include day labouring work, loading and unloading work in the vegetable market, plying cycle rickshaws, making beedis or brooms. Men could earn around Rs75 to 100/- (US\$ 2) a day; for women the earnings would be Rs45 to 50/- (US\$ 1). Some people, mainly

women and children, may work at home doing beedi work, rolling *agarbathis* (incense sticks) or making pappads or other food items. Men who do the beedi rolling are paid Rs75/- for rolling 1000 beedis, while women who stick labels are paid Rs5/- for sticking 1000 labels.

Smoking and drinking alcohol are very common in this area, and so is mental illness. Common health problems include infectious illnesses, coughs, colds, fevers, diarrhoeas as well as chronic problems like diabetes, hypertension, and tuberculosis. Poverty is accompanied by malnutrition, poor housing and a sense of living constantly on the edge of survival. There are social problems, too; and illness is often connected with domestic violence and family breakdown, accompanied by frequent stories of women and children who are battered, fathers who have left home, or young wives packed off back to their mothers when they became ill or unable to cope.

In India, 75% of all health care is private, with repeated surveys providing evidence of large-scale over-prescription of drugs. In this context, 'being ill', can spell economic disaster. At the main hospital, for example, it costs Rs1000/- a day (US\$20) to keep a premature infant alive: but how can somebody on a daily rate of Rs50/- (US\$1) afford such a sum? The lucky ones have family members who will help. But generally, the answer is to borrow from a money-lender who will charge a monthly interest rate of 10%. It is therefore not surprising that health care has also been identified as the leading cause of rural indebtedness in India.

The way out of the slums is education. But children are often kept at home to care for the younger ones, to do odd jobs at home or

(very important) to be sure to be present to fetch water when the weekly supply is turned on. There is a high drop-out rate between middle school and high school. Girls, in particular, are often encouraged to leave school to look after children or sick relatives, and the desirability of early marriage often puts paid to their hopes of further education.

“But that’s only one side of the story,” says Dr Sara. “Yes, there is despair; yes, there is helplessness. It’s true that many people feel defeated by their circumstances. When every possible avenue seems closed to you it’s not illogical to feel there’s no hope. I find it easy to see why young men turn to sex workers, or to alcohol, or leave home. And yet. Visit – say – the neighbourhood of Suriyakalam, less than ten minutes walk from the hospital. Here you encounter all the factors described above. But what you come away with, primarily, is a deep admiration for the resilience, good humour and resourcefulness of the people themselves.”

1.4 Moving the horizons

“It’s with this resilience, this inventiveness, this will to move the horizons, this basic life-force that LCECU seeks, in its work, to engage,” says Dr Sara. “We don’t want simply to provide services: in any case, the sheer scale of the health needs would make this an unrealistic aim. What we want is to develop partnerships with communities that bring people together and help them meet the health needs which they themselves know they have. We see this approach as falling into the category of family medicine, not (as in the West) within relatively empowered communities, but among the poorest of the poor, where the idea of *health* is often obscured by pressing concerns about *disease*, its treatment and its economic implications”.

But as Ida Scudder observed so long ago, the knowledge and experience needed to understand and respond to the health needs of a population are not acquired only by sitting in a clinic waiting for patients to come. They are strengthened by personal encounters with the environment itself, the people who live there and their struggles to live in life-enhancing ways. Accordingly, in 2002 a community outreach service was set up, in collaboration with the Department of Physical Medicine and Rehabilitation (PMR), and with the support of WHO's SEARO⁵ and the Humane Research Trust in the UK. Volunteers were trained to identify and respond to the needs of people with disability in their own communities, with this needs-based integrated rehabilitation service supplemented by the availability of referral services to Ida Scudder Ward and PMR.

In the event, community-based rehabilitation (CBR) proved to be an extraordinarily fruitful entry point for a family medicine programme. Trained in a particular discipline, the volunteers began over the years to take on a much broader role in relation to health care challenges in their communities, and in promoting a good liaison between the community and the hospital. In 2006 a community health physician and then a social worker were added to the outreach team. This increased capacity made it possible to follow up the problems that were identified by the volunteers or encountered in the hospital, and to support local people in developing programmes that are of benefit across the community. So far, these have included life skills programmes for youth and school students; home visits and home based follow-up; improved TB control through better community based follow-up; a community based clinic for elderly and disabled people; community

5. South East Asia Regional Office

based meetings for young mothers in two slum areas, where their children can be weighed and members select topics for health education; health screening camps organized by the CBR volunteers; and medico-social work that includes job placements, assistance in accessing social service schemes, counselling, and liaising with other NGOs.

The work of the health centre has been greatly enriched by the increased integration between hospital and community, and the new networks of contacts that have grown over the years. But LCECU is a small unit. It aims to treat people either for no money or for a minimal fee that they can afford. In comparison with the need, though, its staff is small and its resources basic. It is just not possible to do this work without building flexible, responsive partnerships with other community-based organizations with shared values and aims. These rewarding friendships include – for example – the coordinator of a local relief organization, a couple of local head-teachers, the staff and students of Ida Scudder School, elected ward councillors, representatives of social services, the director of a local orphanage, a family which donates freshly-prepared daily lunch packets for people in the ward or outpatient department. And so on. There are also those people, many of them very poor themselves, who quietly and regularly donate money to the hospital, intended (perhaps) for the support of malnourished children, or as contributions to those who need referrals but cannot afford the hospital fees.

There are times, though, when smallness is an advantage. Because it is flexible and non-bureaucratic, the centre is able to respond to need and take up opportunities: a flexibility that is apparent in a number of the case studies in Part 2 of this book.

Teaching is central to the life of LCECU, as it is to CMC as a whole. Medical students (undergraduate and postgraduate) are posted here, as well as visiting students from many countries in Europe and Asia, Australia, UK and USA. Interns spend a week of their training in the unit. Nursing and allied health students do postings, and two people have based their PhD theses on its work. Customized training programmes in CBR are carried out, on request, and faculty from the unit have participated in the 2-year distance education programme in family medicine. The distinctive feature of all these initiatives, highly valued by participants, is the depth of learning that becomes possible when – in addition to seeing a patient sitting in a clinic – one is able to go out to their homes and begin to understand what it really means to have TB or be sick or malnourished or poor or diabetic in this particular environment. Many interns have described the sudden deepening of awareness as a life-changing moment in their own journeys towards becoming health care professionals.

1.5 Family medicine in an urban health centre

The term ‘family medicine’ can be used interchangeably with such terms as ‘family practice’ or ‘general practice’. It is a term that may be used differently in different contexts: for example, in Western environments, where health and disease are understood in more individualistic ways than they are in – say - India. Basically, all these terms refer to a clinical speciality that offers comprehensive primary health care to individuals and families, in a way that integrates the biological and clinical, socio-economic and behavioural, emotional and spiritual aspects of life. There are a number of key words which are often associated with family medicine, and in this section, they appear in *italic script*.

The distinctive feature of family medicine is the fact that it involves a *holistic* understanding of and response to each individual and each family, in relation to the community they come from, and the health challenges faced by those communities.

It is *accessible* and *affordable*, responding to the full range of health conditions, in the belief that 90% of these can be managed at the level of the health care facility. It is *comprehensive*, in that it is geared to respond to multiple conditions and pathologies, including rehabilitation and palliative care; and as part of this process it promotes health and well-being through *mobilising and educating communities* and their members to discern and use the resources they already have for purposes of health promotion and disease prevention. It is *continuous*, in that it seeks to support individuals and families over the span of a lifetime, rather than just in terms of one episode of ill health.

Family medicine is *integrated* on a number of levels. It provides access to tertiary medical or surgical care where this is necessary, managing the interface with other specialities and advocating for the patient; it helps the patient to make efficient *use of other services* within the health care system; and it is alert to the potential of communities to respond in positive ways to the particular challenges they face. It is also *personalised*, in that it adopts a *person-centred approach* in which the individual is valued, the family history is known, the patient is involved in taking decisions, and the relationships with the health care facility and its staff is one of trust and friendship.

The family physician is a *generalist*, who does not normally claim to have specialist knowledge or expertise. What he or she offers is not cutting edge technology or particular skills. At the centre of

the encounter, rather, is a *relationship*. What the family physician knows about – which she or he specialises in – is the patient and the patient's concerns. This does not mean that family physicians are super-doctors. Neurosurgeons, gynaecologists and psychiatrists will always be needed. Rather by dealing with common illnesses and *referring appropriately*, the family physician helps specialists to use their time more effectively in responding to patients who really need them.

Finally, the practice of family medicine is defined by the *geographical area* it serves. It is this intimate knowledge of a particular *context* that enables the family physician to have insight into the patient and his or her situation. And this means that there are, in family medicine, no universal answers, no '*one-size-fits-all*' solutions. There are just too many variables. There is the patient and his or her physical or mental condition; there is the family situation with all that it implies in terms of caring capacity; there is the cultural, economic and social impact of illness; there is the environment and its hazards and there are the exacerbating factors or potential for response that exist within the community itself. Further variables include the resources existing within the health care facility, and the accessibility of referral services. And that is what makes the practice of family medicine so stimulating and exciting. That is why those who work in this field so often say they would not wish to be anywhere else.

It is this excitement that we want our readers to share, as they engage with these stories from the world in which we work. Along with our patients, our fellow members of staff, our friends, our partners in the community and our invaluable colleagues in CMC's tertiary hospital, we welcome you into our world.



Abba Poemen said about Abba Pior that every single day
he made a fresh beginning.

Abba Sisoës said: Seek God, and not where God lives.

Abba John the Little said: We have abandoned a light
burden, namely self-criticism, and taken up a heavy
burden, namely self-justification.

Abba Anthony said: The time is coming when people will
be insane, and when they see someone who is not insane,
they will attack that person saying: You are insane
because you are not like us.

Sayings from the Desert Fathers



Part Two

CASE STUDIES



There is no greater agony than bearing an untold story
inside you.

Maya Angelou





This is my prayer to You O God-Strike,
strike at the root of penury in my heart.

Give me the strength to bear lightly my joys and sorrows.

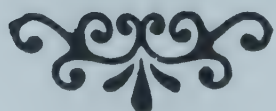
Give me the strength to make my love fruitful in service.

Give me the strength never to disown the poor or bend
my knees before insolent might.

Give me the strength to raise my mind high above daily
trifles.

Give me the strength to surrender my strength to your
will with love.

Rabindranath Tagore



2.1 Volunteers: the eyes and ears

The outreach activities of the urban health centre depend for their effectiveness on the presence of its team of loyal local community-based volunteers. In 2002, in collaboration with the Department of Physical Medicine and Rehabilitation, the urban health centre took the decision to set up an outreach programme in the urban areas it served. 'Rehab' volunteers would receive three years of training, supported by WHO's South East Asia Regional Office (SEARO) and the Humane Research Trust in the UK. The volunteers were asked to carry out a survey of disabled people and their lives. For this, it needed men or women who had the confidence of community members, and who attracted sufficient trust for people to be willing to share confidences.

These local volunteers – all women, and all chosen from their own urban areas – are effectively the backbone of the outreach work of the urban health centre. The skills training and the experience of working as part of a health team have often led to them moving into leadership roles in their own communities, working under their own initiative, responding to new situations and liaising effectively with other services.

In having 'rehab' as an entry point, they found, in disabled people, a group that is generally hugely disadvantaged and often extremely isolated. For most of their patients, there is no possibility of a 'cure'. What is needed is to increase the disabled person's capacity to live productively in the context of his or her own home, family and community, and also to help families to develop ways of adapting and helping. Philosophically, this

is a challenge because addressing disability demands that we think differently about what it means to be 'healed' or 'whole': a shift of emphasis that can colour one's whole attitude to health, wellness and the value of life.

Maryamma, Neelavathy, Ajji, Ruth Pushpa, Ruckmani, Suryakala and Mary are all community-based volunteers working with the urban health centre's outreach team. They identify problems in their areas, accompany people in accessing help, and liaise with the hospital and other support services. All of them completed the original three-year training in Community Based Rehabilitation, gradually moving towards health promotion generally.

The stories are remarkably similar. Ruckmani says, "I was always in my home. I wanted to help others, but had no idea how to do it. But now, by working for poor people, I have respect in the community. I used to be anxious about going out, but now people look for me. I have the courage to talk to others". Or else, in Ruth Pushpa's words: "In 2002, I didn't know anything. Today I know so many things, from doing all this. I always had the desire to help people, but I used to get very impatient. At first it was difficult but now I can deal with whatever happens patiently".

Ajji used to be a beedi-worker. "When the doctors came," she said, "I thought they had come to do something for us, but really they were suggesting that we did something for ourselves and for one another. They said you had to be able to read and write in order to be a volunteer, but when they saw my enthusiasm they agreed to take me. And my husband agreed too. I don't know how to write, so I dictate my results to my son. Now I have a lot of

knowledge and skills about disability, and that gave me a good base for working in general health.”

Neelavathy’s paid work is selling cloth, but she was keen to spend the afternoons doing something else. “I have had many blessings through this work”, she says. “Apart from disability, I learned about general illness and poverty alleviation, and about the importance of gender development. Before, I used to sit down and cry with problems; now I face them. I am still learning, though: yesterday at a public meeting I was asked to speak, and I was confident, whereas before I would have been shaking and shy. Now I have been selected through a government programme as a leader in the community. Things are changing. People need training. I am privileged, but I want to hand it on to others. If you train one, you train many”.

Maryamma’s family thought she was too old to do anything useful. “They all said I was too old for this job”, she says. “Not just my family but the Scudder team as well. But I persuaded them. And because of the training I learned about disability. Many can’t come to hospital because they have no money. So I learned to look after them without money. I see people with strokes, blind people, and I do tests. It is so good to see changes happening, like people learning to walk. It is an honour to make people better. So my family can’t dictate to me any more!”

Suryakala says she “had a mind to serve, but studied only up to 8th standard, so I couldn’t get a salaried job”. It was only when she went on the survey that she realised there was so much disability in the area. “Now”, she says “I look after people with seizures, different disabilities, and a need for physiotherapy. Today I am

able to give suggestions about problem solving, and getting services from government such as how to apply for disability certification”.

Mary Jebamani has been one of the most active and productive volunteers. She has initiated many things, especially with young men and women. She has taken a lead in setting up an elderly and disability group in the Old Town area, and also a mother and child group when mothers can come with their babies, get together, discuss health issues, and have their babies weighed regularly in their own area. She has learned a lot, working in the community, and getting people to discuss the resources they have for helping each other. “Until 2002,” she says, “when this programme started, I spent my life being quiet inside my house. Now I can solve problems, ask questions. I can ask to use the resources provided by the hospital. I have knowledge and a lot of courage now. I know many things that educated people know”.

Much as she loves the work, Mary Jebamani is now struggling with a decision about whether to move on to paid work which would be very useful for the family. In addition, the character of the urban health centre’s involvement in communities has changed radically, with the training of the young people, the expansion of partnerships with schools and other organizations, and the knowledge that informal networks of contact and empowerment are developing and expanding all the time. This raises many questions. Who is a volunteer in this context and in the present situation? How does the centre structure its community presence in the future? To what extent does one need to ‘own’ the network of community contacts with which one works? How informal can these be, without losing accountability and effectiveness? And again, the knotty problem confronted all over the world by

organizations that work primarily with volunteers: what are the ethics of not paying people who are giving so much time and effort to a job, especially when they themselves are extremely poor?

Many of the case studies in Part Two highlight the important role that volunteers play in these communities. They run successful, regular one-day health camps, where the residents of whole areas converge. They have collaborated with school-children to organize a massive weighing exercise, involving all the under-fives in Old Town. This featured a huge weight chart, where each child's weight was entered, so that at the end of the exercise the whole community could see the nutritional status of their children, and this in turn would form the basis for a child nutrition programme. On yet another day, five of the volunteers brought along 30 boys and girls who wanted to train to help disabled people in the community. The volunteers looked on proudly. They know the achievements are partly theirs: the work of spreading the word, motivating a new generation and giving them confidence, drawing more and more people into a network of support which is life-giving and hope-creating in a context where many people's lives seem to be without life that has any degree of quality, and also without hope. Soon they are going to organize sight and hearing tests for the populations of their areas: suitable indeed for women who have become the eyes and ears that link their communities to the urban health centre.

QUESTIONS

1. What makes a person volunteer to help others even when they themselves have difficult lives?

2. How would you describe the relationship between the volunteers and the health centre? Would giving the volunteers a small sum of money on a regular basis change this relationship?
3. Is it ethical not to offer payment?
4. How can the volunteers be supported and empowered in their work?
5. How could one replicate the way of working described here in rural areas or other urban places?
6. Does working in partnerships with communities mean that a health programme must give up fixed agendas, standards and ways of working?
7. In this project the work continued to grow in many ways, even after the funding stopped. What factors encouraged this to happen?



Let your love play upon my voice and rest on my silence.

Let it pass through my heart into all my movements.

Let your love like stars shine in the darkness of my sleep
and dawn in my awakening.

Let it burn in the flame of my desires and flow in all
currents of my own love.

Let me carry your love in my life as a harp does its music,
and give it back to you at the last with my life.

Rabindranath Tagore





ETERNITY

Eternity is not endless time or the opposite of time. It is the essence of time.

If you spin a pinwheel fast enough, then all its colours blend into a single colour - white - which is the essence of all the colours of the spectrum combined.

If you spin time fast enough, then time-past, time-present, and time-to-come all blend into a single timelessness or eternity, which is the essence of all times combined.

As human beings we know as a passing of unrepeatable events in the course of which everything passes away - including ourselves. As human beings, we also know occasions when we stand outside the passing of events and glimpse their meaning. Sometimes an event occurs in our lives (a birth, a death, a marriage - some event of unusual beauty, pain, joy) through which we catch a glimpse of what our lives are all about and maybe even what life itself is all about, and this glimpse of what "it's all about" involves not just the present but the past and future too.

Inhabitants of time that we are, we stand on such occasions with one foot in eternity. God, as Isaiah says "inhabiteth eternity" but stands with one foot in time.

Frederick Buechner
Wishful thinking: A Seeker's A B C.



2.2 Murugan: Seeing things differently

Over the years, the 'official' volunteers have become leaders. In doing so, they have opened the door for many others – particularly young people - to come forward and take on leadership roles. Among these, blind Murugan's story raises many questions about quality of life, about what it means to be able to 'see', and about our whole concept of what it means to be a leader in one's community. It also raises questions about what it is to be whole, and about how we define incapacity. Murugan has – on the face of it – nothing; he sees nothing, except to be able to distinguish between light and darkness. On another level, he has much; and he sees much. When a group of medical students met with him, they commented: "He is a contented person." Or as he says himself: "I have life. And the gift of God is eternal life".

It is the second Thursday in the month, which means it is the afternoon when a clinic is held in Old Town for the elderly and disabled people of the area: the two groups identified, in a survey by young girls in the community⁶, as the ones who had the greatest difficulty in accessing health care. Both groups, they found, were isolated, marginalised within their communities, and both found it quite impossible to get to the hospital. With the help of the outreach team, occupational therapy students and the local volunteer, the girls set up a monthly clinic in a local church, at which people could get together and chat, share problems, and have a general health check including blood pressure and blood sugar monitoring. Some problems and worries could be sorted out then and there:

6. See Ranjit : Ripples of life, in Case Study 2.9

others could be referred to the outpatient department at the urban health centre.

On this particular Thursday, the team arrives, a little late, to find the gate locked and the building guarded by a fierce and uncompromising male goat. Soon a young woman appears with the keys. Cautiously, members of the team edge past the goat and let themselves in. And within minutes, the sounds of singing and tapping are heard outside. With a whoop of laughter, in comes blind Murugan feeling his way forward with his retractable white stick.

Murugan has been blind since he was thirteen years old, though nobody seems certain why this is, nor is he able to answer this question. He has done thirteen 'trainings', he says, in various skills, so he knows how to do a lot of things. He would like to be a candle-maker, but he cannot raise the Rs5000/- it would take to set up a business. Now he turns his head to left and right, in sudden jerky movements. "Nobody has come!" he exclaims. "Where are they all? I will go on my rounds: they will soon be here". And off he goes, singing "Thank you Jesus".

And one by one, elderly men and women start to hobble in. Many walk painfully, sink exhausted to the benches along the wall, or else lie down on the floor mats while they wait. They have trouble with knees, hips, breathing, blood pressure, remembering to take tablets, getting enough to eat, or just the effort required to keep going generally.

Then, on another burst of song, Murugan is back. He has played a crucial part in setting up this clinic. He knows everyone in the

community, and he knows where the people are who are in need. He also knows great tracts of Scripture. God, he says, has told him: "I will accomplish things too high for you, things you do not understand". God has said, "Do not be afraid, I am with you always". "So then I cannot be afraid", says Murugan. Asked how he has learned to quote the Bible, he replies: "I learn the words. People read to me. My sister reads to me. And I remember. It is called 'reading by hearts' ". Asked about Braille, it is clear that this is something he has no concept of at all.

Murugan has also taken responsibility for organizing the young people who want to get involved with issues of disability in the community. Although the training takes place a half hour's bus journey from the slum area where he lives, Murugan is responsible for bringing people together. People tell the story of the day when Murugan turned up at the first networking meeting for people with disabilities, having heard that another blind man was going to be there. This man, it seems, had said he would not use a stick, and to Murugan this seemed heartbreaking. So he came carrying two white sticks, one of them to give to this man who didn't know what new life this very simple aid would bring. "I have two", he said. "I do not need two. You take it and you will be able to see, like me".

QUESTIONS

1. Volunteers have been described as the 'eyes and ears' of the outreach programme. How would this apply to Murugan?
2. How could the urban health centre help Murugan himself?

3. What does this story tell us about the human capacity that exists in communities?
4. How and what do we see as we go about our daily routines in providing health care? Why?
5. How does Murugan's way of 'seeing' speak to you?
6. "*What we see depends on what we are looking for.*" How does our attitude affect our choices and behaviour in our personal and professional lives?
7. What light does the story throw on the ways in which we perceive disability?
8. If you used this story as part of a teaching programme for health professionals, what lesson/s would you hope they would learn? If you are student yourself, what have you learned from it?



It was said about one brother that when he had woven baskets and put handles on them, he heard a monk next door saying: What shall I do? The trader is coming but I don't have handles to put on my baskets! Then he took the handles off his own baskets and brought them to his neighbour, saying: Look, I have these left over. Why don't you put them on your baskets? And he made his brother's work complete, as there was need, leaving his own unfinished.

Sayings from the Desert Fathers





The day will come when after harnessing the ether, the winds, the tides, gravitation, we shall harness for God the energies of love. And on that day for the second time in the history of the world, man will have discovered fire.

Pierre Teilhard de Chardin
The Evolution of Chastity



2.3 Mari: The challenges of community-based psychiatry

Long-term mental health problems are extremely common in poor urban areas. But for poor people to access psychiatric care they must get themselves to the hospital, they must pay and they must be admitted with another family member. The urban health centre is fortunate in having excellent relations with the newly established rehabilitation and outreach unit at the department of psychiatry. Here, the consultant psychiatrist is keen to develop systems for treating people in their own contexts, in ways that may not be officially regarded as 'best practice', but which are nevertheless appropriate, manageable, and take advantage of the capacity that already exists within the family and the community. Inevitably, this involves challenges to traditional approaches to psychiatric care.

Mari lives with her parents in a dark slit of a home, little more than a shed propped up by a next door house. She is 25, and for ten years she has been mentally ill. When the team first encountered her, she was violent and uncontrolled in her behaviour, refusing to eat normally or to wear clothes, and not recognizing her parents. Other children would scream when they saw her, and neighbours kept away, fearing the contamination of contact with this marked family. On one occasion, Mari set fire to herself, resulting in burn contractures to her arm and scarring down one side of her body. She tried to run away, and for the family, that might in fact have been a relief.

However, the family persevered, borrowing money to go to healers of different kinds, and to doctors. They often had to do without food in order to get there and to buy drugs, only to see Mari become

violent and distressed when they tried to make her take them. Exhausted, they gave up. It was clear that no amount of force or cajoling would make her swallow oral medication. In 2002, a volunteer trained in community based rehabilitation identified her to the urban health centre as a person with ‘strange behaviour’, who might possibly be helped through the project. To their astonishment, the family turned down the offer and the team felt obliged to accept this decision.

Over the years, the doctor and social worker from the urban health centre became familiar figures in the area. One day, in 2008, they were passing through when the father emerged from the dark interior and said: “Please help us”. Mari was now living in a tiny, dark, locked ‘cell’ with a floor of coarse sand and a doorway so low you had to bend double to enter. Here she spent her life, lying on the floor, smoking beedis and sleeping. The only words she spoke were ‘Mari’ and ‘beedi’. The stress on her parents was extreme. Her mother had to stay at home to care for her. Her father has pulmonary problems brought on by years of smoking. The whole family was isolated by the girl’s illness, which many people saw as possession.

There was no question of getting Mari to the psychiatric hospital. To be admitted in such a centre, they would have to go by private transport; she would have to stay there with a family member; and she would have to pay. The family could not possibly afford it. So the team discussed the situation with a consultant psychiatrist from the new rehabilitation and outreach unit of the psychiatry department. She would make a home visit, she said, and see what could be done without admission to hospital. Mari wouldn’t take tablets, so she suggested that they try injecting an anti-psychotic

drug, fluphenazine, once a month for six months, and see what happened. This would cost no more than Rs. 25/- (US\$0.5) a month. On the first occasion, it took four of them to hold her down as they administered the injection.

What the team were hoping for was a gradual, possibly almost imperceptible improvement over a period of time. In the event, they were astonished by the speed of the improvement they saw when they visited the family. The transformation was extraordinary. Within a month, Mari was up and about, dressed, eating by herself and speaking in short sentences. They had been dreading a repetition of their previous experience in delivering the injection, but this time she came forward and asked for it.

Three months later, she was fetching water and washing dishes. She was able to take tablets as well as the monthly injections. She could go to the shop for small items; the small children had stopped running away when she appeared, and the neighbourhood was beginning to take her presence for granted. “They serve her first when she goes to the shop”, says her mother, “and she is never cheated”.

The volunteer, who knows the family, says: “The problem is that people do not have good information on mental illness. The family believed that the illness of this child was the result of possession. They tried all kinds of things to get rid of the possession: beating, abuse, religious exorcisms, restraint. It is difficult to imagine the level of stigma. Sometimes they said: ‘It’s because she isn’t married’ ”.

But for the psychiatric consultant, this whole story raised huge questions. “Because of this experience”, she says, “there has been a whole paradigm shift in my mind. What I’m interested in is not just the fact that the girl is better. Before, I would have thought it was terrible that this child had been locked up. But I have seen the home and met the family. I have become aware, more, of the strength that has kept this family alive for all these years. So much strength and resilience is there, but that is something we rarely see in hospital. It was a revelation to me. It would have been so much easier just to have let her run away and be rid of the responsibility. Why didn’t they do this? I have come to think that what we might see as cruelty is in fact love”.

“The lesson”, she says, “is that even if you can’t produce a complete cure, and even if you will never know exactly what the diagnosis is, there’s a lot you can do for mental illness, without spending much money. If you don’t have money or resources for what we call ‘best practice’, then you have to look at the problem in a different way. Somebody has to look after her. It can’t be the doctor or the social worker or the volunteer (although they can all help): so it has to be the family. What are needed are mechanisms to strengthen community capacity, knowledge and skills, and encourage people to help each other”.

“I sometimes feel I am myself disabled by my professional knowledge. Now I tell students: ‘There is no single, obvious answer. You must know the context of people’s lives. Socio-economic issues are central: how do we treat mental illness *in a situation like this?* We are not called just to sit in a hospital. Students need to go on community visits. The danger, for us health

professionals in hospitals, is that we believe that our concept of 'the best' is **always** what is right. It is a symbol of the gap between **holistic and specialist care**. What I have found myself doing with the **urban health centre**, is providing psychiatric support and back-up to a family medicine team whose aim is not only to bring health care to the people, but also to encourage them to find the sources of life in themselves and their own families and communities”.

QUESTIONS

1. How would you feel and what would you do if your offer to help was rejected? Should the urban health team have been more proactive? Why?
2. In this poor, urban setting, what are the particular problems attached to mental illness (as opposed to physical illness)?
3. How might this story have been different in a rural PHC?
4. Why did it take so many years for Mari to access the services of a nearby premier mental health institution in a meaningful way? What might have helped?
5. What would you want students to learn from reviewing this case study?
6. Can one be disabled by one's professional knowledge and standards of best practice?
7. How can doctors and health workers encourage people to find the sources of life in themselves and their families and communities?



My Life is full of apprehension
And I am engaged in a struggle
that takes all energy.

Sometimes, I am just hanging on
in spite of myself.
Looking for signs
and hoping for miracles.

I am surprised that I am.
That I am still here
In the middle of life.

And I become aware of grace.

Ulrich Schaffer
Into your light



2.4 Binila: Chronic illness in a woman's world

In treating patients with chronic or long-term conditions, staff will generally expect a level of cooperation from the sick person and their family. It is easy for busy health professionals to feel angry or to blame patients who fail to keep to treatment regimens or to make regular visits to the clinic. But blame is not always an appropriate response. It may take a home visit and a personal encounter with the family context to bring one to an understanding of the difficulties the patient is facing. And in most cultures, one of the biggest obstacles to health is simply 'being a woman'. It is no good thinking that Binila's problems will be solved just by handing out medicines, important though that may be.

All over the world, gender is a factor in health care. A holistic understanding of Binila's condition makes one realize that it is not just the disease but the whole context of her life that is compromised. What do concepts like 'shared parental responsibility' mean to a young wife who has to clean the house, wash clothes, cook food, look after a child, get him ready for school, collect water from the nearby bore well, fight for the municipal water when it comes once a week, manage a household with 20 rupees a day and deal with a husband whose interactions with her were gradually restricted to beating her up and abusing her verbally, sexually and emotionally, often in front of her child and the neighbours?

Binila came to the urban health centre for treatment of diabetes. But her visits to the diabetes clinic were irregular and her sugar levels were not controlled. When staff found that neither lectures

nor persuasion succeeded in improving her compliance, they arranged a home visit to the dark, cramped little house in the Old Town slum area where she lives with her husband, her parents-in-law and her little boy. Binila's story made it abundantly clear what the problem was.

A bright, happy child, Binila grew up in Old Town, her parents (who were day-labourers) working hard to educate their two daughters. But then, one day, the sixteen-year-old Binila announced that she wanted to stop school and get married to a neighbourhood boy of her choice. That he was illiterate and did not have a steady job was not a problem for her. "Never!" said her parents; and when she proved adamant, they packed her off to her uncle's house in another town where she could continue her studies. Angry and resentful, she ran away from her uncle's house intending to get married. But then her parents threatened to take her to court if she married before she was eighteen, and she had to live in a local welfare centre until she was legally able to marry Arun. She had been so sure that once they had a baby, her parents would come around and everything would be all right. But for her parents, her marriage was the last straw. Girls, especially, are expected to obey their parent's wishes, most importantly in relation to marriage. They made her sign a bond stating that she was not their daughter anymore and had no claim to the family or its property.

Undeterred, Binila set up her home and was overjoyed when she became pregnant. For a while things went well. Her in-laws who lived with them were supportive and the little baby boy gave them all a lot of joy. Arun too was working regularly and earning around Rs60/- a day. She suspected he was drinking more and more, but she was so busy with the baby and the household chores that she

ignored it. Besides, she was feeling tired and was losing weight. So she visited the urban health centre. To her dismay, they said that she had diabetes, which would involve being on a diet and taking regular medications for life. This news threw the family into disarray. Her mother-in-law was helpful, but Arun became more and more erratic, spending most of the money he earned on alcohol, giving her only Rs. 20/- for household expenses. When she asked for money for medicines, Arun became abusive, and the beatings became a regular feature in the household. Binila began to fear having another child, but this too drove Arun into a rage. His friends, he said, were teasing him; saying that having only one child implied he had lost his 'manhood'. "My life was becoming a living hell", said Binila.

For some of the neighbours, it seemed that she deserved her fate for disobeying her parents. Her husband was of a different caste and community; he was violent and often drunk; she should never have gone against the family, they said. Having married him, though, he was now her husband, and he should be like a god to her. She had made her choice, and now she must live with it. As Binila's parents live in the same street, she sees them every day, and it breaks her heart not to talk with them and see them take her son in their arms.

Binila had come to the centre with diabetes. But it had become quite clear to staff that it was not possible to treat this presenting condition without also addressing the other problems in her life. Her priority is to make sure she remains as healthy as possible so that she will be there for her son; but to do this she must find money for her medications, and she must find time to visit the clinic regularly and meet the doctor. She needs to find strength

within herself to face a multitude of challenges, among them living with an alcoholic husband, being disowned by her parents, managing a house with Rs. 20/- a day (less than US\$0.5), choosing not to have second child even if it means going against the norms of the society she lives in, fighting the weariness, despondency and depression that sometimes creep up on her. Her one hope is in her son, who (with the help of her in-laws) is attending an 'English medium' school. And somewhere in the back of her mind is the dream that her story will, after all, have the fairy tale ending that always comes about in the movies.

QUESTIONS

1. How can you be of help when women and girls find it difficult to follow instructions about their medical care? How would you help Binila?
2. 'Gender' issues are sometimes presented as problems that only affect women and girls. Is this true, or is the whole community affected?
3. If this story were from a rural context, would there have been differences?
4. How would you build awareness of these gender issues into your professional encounters with patients?

5. If Binila experiences only rejection from her family and accusation from professionals, what happens to her sense of self worth and desire to look after her health? What does she need to hear instead?
6. In working on this case study with students, what lesson/s would you want them to learn? If you are a student yourself, what important lessons have you learned from it?



Homelessness

We lie in our beds in the dark. There is a picture of the children on the bureau. A patch of moonlight catches our clothes thrown over the back of a chair. We can hear the faint rumble of the furnace in the cellar. We are surrounded by the reassurance of the familiar. When the weather is bad, we have shelter. When things are bad in our lives, we have a place where we can retreat to lick our wounds while tens of thousands of people, many of them children, wander the dark streets in search of some corner to lie down in out of the wind.

Yet we are homeless even so in the sense of having homes, but not being really at home in them. To be really at home is to be really at peace, and there can be no real peace for any of us until there is some measure of peace for all of us. When we close our eyes to the deep needs of other people whether they live on the streets or under our own roof- and when we close our eyes to our own deep need to reach out to them- we can never be fully at home anywhere.

Frederick Buechner
Wishful thinking: A Seeker's A B C.



2.5 Arun Kumar: A hopeless case?

Evaluations of public health and primary health care programmes tend to focus on numbers, statistics and formal processes. For example, you may make an epidemiological map of an area, do a needs assessment, design a response, calculate how many people can be helped, work out what resources are needed and where they will come from, and keep a record to show how your actual outcomes measure up to the projected ones.

In family medicine, context is just as important, and so also are the needs of the wider population. But the entry point is a different one. Family medicine involves addressing the joys and woes of particular families and individuals, not just as representative statistics, or as examples of more general health and social challenges, but as named human beings whose lives and deaths are valued and valuable in themselves. It involves making friends and forging partnerships with others, so that the family practitioner's response becomes just one dimension of a joined-up, holistic, organic response in which the catalyst is the suffering family or individual. This culture of shared and compassionate response raises questions of priorities which are powerfully demonstrated in the story of Arun Kumar, which follows.

In the centre of the city of Vellore, just outside the main CMC hospital campus walls, there is a nightmare traffic intersection, permanently jammed with trucks and autos and cars, with two-wheelers dodging murderously between them. The pedestrian is assaulted by revving engines, the cacophony of horns and the

(futile) broadcasts of the policeman with megaphone and the facemask, standing on a dais to one side. No sane pedestrian tries to cross the road at this point.

One steamy midday, the owner of a small medical store was relaxing on his front step when he observed a strange sight. Shuffling on his bottom, backwards and forwards across this intersection, was the figure that looked barely human, but was still, recognizably, a man. The storekeeper realised that he knew this man: he was a stranger to whom he had been giving food. Looking more closely, he noticed that the man's right leg appeared to be covered by a festering wound, full of maggots. Occasionally the man would stop his bottom-shuffling, pull a maggot from the wound and eat it.

Unsure what to do, the storekeeper called a friend. Chandrasekhar runs a local NGO, Udhavum Ullangal (the Helping Hearts Trust), which is dedicated to helping poor and destitute people by building alliances with other local organizations. The two men picked up the stranger, took him to the roadside and called a local doctor to whom Chandrasekhar often goes for help. The doctor cleaned the wound and tried to dress it, but the dressing was instantly torn off and thrown in the gutter. In these circumstances, they realised that they couldn't treat him on the roadside. So Chandrasekhar called another ally, a psychiatrist from the Department of Psychiatry's outreach and rehabilitation unit. But how could she help? Such a patient did not fulfil the criteria for admission to either the main CMC hospital nearby or the mental health centre. The patient had no relative to care for him and no money to pay. So the decision was made to take him to the urban health centre, which was smaller

and more flexible, and was therefore able, when needed, to relax the rules and admit this 'stranger from the street'.

Here, nurses placed the stranger in the hospital's small isolation ward, and everybody got together to clean, bath and shave him, feed him and to dress the wound. This turned out to be a thankless task: he passed faeces and urine directly into the clean nightwear, smeared faeces on the walls, tried to eat it, and began rooting around in garbage cans for scraps of food. He seemed to understand a little Hindi, but he could not speak in full sentences. His behaviour, says the psychiatrist, was "characteristic of a regressed schizophrenic". They started treatment accordingly. Within days, he was talking in full sentences, accepting help and using the toilet. His name, they discovered, was Arun Kumar, and he came from Chattisgarh. It wasn't until much later, when he was restored to something more like himself, that he suddenly asked for a pencil and paper and wrote down an address for them. The staff were determined that he should learn to walk normally, instead of shuffling around the hospital on his bottom. 'You walk and we will give you *bhajis*,' they ordered.

However, they were still left with the need (common to Indian hospitals) for a family member to take responsibility of day to day care and provision of food. Udhavum Ullangal took on this role, finding the small amount of money needed to pay a woman (herself abandoned and destitute) to live in the hospital and look after him. This woman 'made this man her own', says one of the doctors. They had no language in common, but they seemed to be able to communicate. Then he acquired another friend in a Muslim woman, the wife of an admitted patient, who spoke a little Hindi. "I don't like this food," he told her (although he was eating it

voraciously); “I would like *dal bhath* (dal and rice).” The next morning a dish of *dal bhath* appeared, which this new friend had made for him. Arun Kumar became devoted to this woman. “When I am well”, he said, “I will take you to my home and show you everything”. “You?” she answered teasingly. ‘Where will you get the money? You can’t even afford to pay for your own food!’”

Then, one morning, they found him unconscious: a stroke, probably. All the ministrations of the doctors and nurses failed to rouse him from the coma that he had slipped into. The psychiatrist was informed and when she arrived, she found nurses, the resident doctors and the two women all crying around his bed. A meeting was held, attended by all the people who had been involved: doctors and nurses, consultants, social workers, the women who had befriended him and Chandrasekhar. What should they do? Should they let him die, peacefully? Or intervene with more tests? None of them wanted to give up on him. In the end they decided to treat him; and with advice from other consultants, a naso-gastric tube was put in for feeding and some medicines given.

Through medical contacts in Chattisgarh, the team managed to track down his sister-in-law. The family hadn’t seen him for ten years. Arun’s parents were dead, said the sister-in-law, and they themselves were poor people. Her husband, Arun’s brother was also dead and she couldn’t possibly afford the fare or the time off work to come to Vellore. ‘Very well,’ said Chandrasekhar, ‘I will be his family’.

Eventually Arun seemed to become a little better; and the first thing he did was to pull out the naso-gastric tube. Should it be put back? Or should he be fed by mouth, sip by sip? Of the team

treating him, some felt it was better not to be aggressive with the treatment; others felt it was not right to be passive. Another meeting was called to discuss the progress and management. But by now the patient had developed a lung infection as well. The group decided to treat the lung infection, but not to replace the nasogastric tube if he pulled it out again. “If he gets better,” said Chandrasekhar, “I will find him a place to live”.

But Arun Kumar did not get better. Two weeks passed, and one morning he died peacefully in his sleep. In order to register the death and bury the body, you have to know who the person is. Because the team had traced the family, permission was obtained from them and Arun Kumar was buried with dignity, like a human being he was. Afterwards, they had a message from a relative, saying: “You have looked after this man better than his own family”.

QUESTIONS

1. In a resource-constrained situation, what considerations might make one decide to spend so much time and effort on a person like Arun Kumar?
2. In this story, the patient died despite so many efforts by so many people. How would you define this outcome? Was it a success or failure?
3. What already-existing networks became visible and connected as people responded to an individual in need? Can you think of similar possible connections in your own environment?

4. How do health-providing institutions make themselves accessible to those who need their services but do not formally qualify for them? What are the constraints, if they decide to do so?
5. What do you mean by 'dying with dignity', and does it matter?



You have made me known to friends whom I knew not.
You have given me seats in homes not my own. You have
brought the distant near and made a brother of the
stranger.

I am uneasy at heart when I have to leave my accustomed
shelter; I forget that there abides the old in the new and
that there you also abide.

Through birth and death, in this world or in others,
wherever you lead me, it is you the same, the one
companion of my endless life, who links my heart with
bonds of joy to the unfamiliar.

When one knows you, then alien there is none, then no
door is shut. O grant me my prayer that I may never lose
the bliss of the touch of the one in the play of the many.

Rabindranath Tagore





I wait out the darkness
The feeling of not mattering to myself,
To others and to the passage of time.

I lose all concerns for my image
All thoughts of expectations
All well intentioned ambitions.

That way I become free to become much less
than I appear to be.
In order to become more than I am now.
I shall use the darkness and time
To be transformed into the light
That you have chosen for me.

Ulrich Schaffer
Into your light



2.6 Lakshmi: Stigma and healing

There have always been some forms of disease that are stigmatized by society. Leprosy is one of these. Tuberculosis is another. Today, all over the world, stigma attaches itself to people living with HIV or AIDS, their families and the orphans who survive them. AIDS-related stigma is accompanied by (and partly founded on) an irrational fear of contamination or infection. Women are particularly likely to be stigmatized and rejected. The story of Lakshmi shows the urban health centre caught in an awkward situation. Among our staff, they say, there will be no stigmatizing of sick people. But they cannot change the society they live in, or alter the attitudes of people in the community. So they are forced to collude with the denial and secrecy that is so powerful an enemy of HIV prevention.

Lakshmi is a flower seller, in her early forties, who sold flowers, until recently, in the shopping street that bisects Vellore's slums and fringes the world of the urban health centre. Her husband got drunk frequently, stayed out late, then came home and beat her. Eventually he left, going to live with somebody else and leaving Lakshmi to care for their son and daughter. Her mother-in-law, with whom she lived, was supportive and took her side. But then she died, and the family was entirely dependent on the Lakshmi's daily earnings of Rs 20 to 30/- (about US\$0.75). She and the children live now in a one-room slum-hut so tiny that you have to crouch to get through the door.

Fourteen years ago, she developed a persistent cough, which turned out to be pulmonary tuberculosis. She entered a DOTS regime, and eventually got better. Two years ago, she had a recurrence of

the disease, but did not appear to be responding to treatment. It is a demanding regime, and a neighbour said she was not always taking the tablets. They began to suspect that she had multi-drug resistant (MDR) TB. In addition, it emerged, she was HIV positive: although just now her CD4 count is around 500, so provided they can cure the TB there is no reason why she should not remain healthy for many years. She does not yet need the free antiretroviral medications provided by the local government ART clinic. The MDR TB, though, demands both treatment and – until she becomes sputum-negative – isolation.

So Lakshmi was admitted to hospital. Unlike many people in her situation, she does have some family support. Her sister is currently looking after the children and managing the flower selling, and bringing Lakshmi food in hospital. ‘To me’, she says, ‘my sister is god’. Because of her sister’s help, her daughter is able to go to school. But Lakshmi does not know what the future holds. She will be in hospital for at least another month. Once she goes home she will have to cook and provide for the family, which she is not able to do now. She is not sure whether she will ever be fit to go back to work.

Lakshmi is in an isolation ward because of her MDR TB, not because of her HIV infection. In the urban health centre, staff are conscious of the damaging social stigma that people face when they have HIV or AIDS: there has been a big movement, especially within the churches, for people with HIV not to be stigmatized. Nevertheless, if the patients or the community knew, they would certainly stigmatize: far more than for the TB, which is much more likely to infect others, although that is stigmatized too. In another hospital, it became known that there was a patient on the ward

with HIV. News spread, reporters came, and the next day they saw the photo in all the newspapers. As a result, the patient was unable to go home and the family had to move to another town.

We do not have a photograph of Lakshmi. This is not because she is embarrassed about her appearance, although indeed she is all skin and bone and looks exhausted. “Supposing the photo gets into the paper,” she says. “And supposing people find out?” One is torn between the absolute priority of protecting Lakshmi and her family, and the knowledge that until people do start to be more open about such matters, the stigma attached to AIDS will never be overcome.

Lakshmi has so many problems: does she worry much about the HIV? “Not so much,” she says. “My family are good to me, and most people don’t know. I am not afraid to die. But I do not want to die before my children are grown up. Who would look after them? Who would arrange a marriage for my daughter? I am their mother, and while they need me I want to stay alive”. The health team’s social worker is in touch with a local organization, run by an occupational therapist / physiotherapist couple, which helps with the family problems encountered by people living with HIV: there is always that possibility. But living with HIV, today, is not about dying: it’s about living. So long as her status remains secret, Lakshmi seems to agree.

QUESTIONS

1. How might Lakshmi’s problems be dealt with in a rural PHC?
2. How do you deal with MDR TB in the family?

3. What is your understanding of 'stigma'?
4. How does stigma affect the course of a disease?
5. What other conditions are stigmatised and what do you think is at the root of the stigma?
6. What emotions and thoughts are likely to fill the mind of a victim of stigma? What impact can this have on their behaviour?
7. How can a health worker deal with the effects of stigma on the patient and the family?
8. Are health workers part of the problem that creates stigma?



Here is Your footstool and there rest Your feet where live
the poorest, the lowliest and lost.

When I try to bow to You, my obeisance cannot reach
down to the depth where Your feet rest among the
poorest, the lowliest and lost.

Pride can never approach where You walk in the clothes
of the humble among the poorest, the lowliest and lost.

My heart can never find its way to where You keep
company with the companionless among the poorest, the
lowliest and lost.

Rabindranath Tagore



Saturday People

To look at the Promised Land from afar and not to set foot
on its soil,

To dream of milk and honey and not to taste the mixture

This was the lot of Israel's greatest prophet.

There are many prophets in the wilderness who die
outside the promised land.

Squeezed between Good Friday and Easter,
Ignored by preachers and painters and poets,
Saturday lies cold and dark and silent-
An unbearable pause between death and life.

There are many Saturday people to whom Easter does not
come.

There are no angels to roll the stones away.

There are many Saturday people in the world today.

Children dying for want of food and affection
brides who bring little or no dowry
mothers who break stones and carry bricks
boat people waiting for the end of the right to asylum
debate

prisoners who die in custody and those killed while trying
to escape

hostages who do not see the light of day and detainees
who do not see a courtroom

tribals evicted from forests and fisherfolk separated from
the sea.

Generations from nations and peoples and tribes doomed
to die without hope.

The prophets who lead the Saturday people die with them
outside the promised land.

There is a cross in every resurrection.
Is there a resurrection in every cross?

S J Samartha
The Pilgrim Christ



2.7 Velu: When poor people need hi-tech medicine

Nurses, doctors and interns all speak of the great satisfaction of working in an environment where the first priority is the response to need. Care comes first. Only then, cost is negotiated. Then, if people can afford to pay, they should pay what they can. The advantage of the urban health centre's close relationship with the community is that the outreach team are able to find out (through volunteers or other contacts) whether stories of neediness are true, and whether people are indeed paying what they can. Doctors, nurses and allied professionals all claim that the relationship with their patients is transformed by the priority given to need: a view that is echoed by both inpatients and outpatients themselves.

There are times, though, when what the patient needs is something that the centre is unable to provide without going back into the 'pay-first, needs-met-later' culture. There are times when low cost care is not enough. For this reason the support of the departments of the tertiary hospital is absolutely crucial to the urban health centre's capacity to provide an effective service to poor people. In its turn, many people in the main hospital feel that the urban health centre serves a vital purpose in making space for poor people within the increasingly specialised, profit oriented environment of contemporary medical practice. Professor Bala Seetharaman is head of nursing services at the urban health centre. CMC, she says, was set up to help the needy people of Vellore Town, especially women and families. "It is part of our mission and our calling that we should support that work, and that there is a space within the hospital where tertiary medicine can be made available to poor local people. This centre is that place."

Velu, who is 35, has been coming to the urban health centre for twenty years. He had developed rheumatic heart disease when he was a child, but it wasn't until he was grown up and a family man that the condition became really serious. In the mid-nineties, his wife left him. He became extremely depressed, and in the ensuing domestic chaos he lost his OPD treatment chart. Believing that he would not be allowed another one, he did not come back until 2002, when a child by his second marriage became sick and needed help.

Normally, Velu works in a bakery, earning enough to support his small family. But his heart condition began to deteriorate, and soon he became incapable of working. When he was admitted to hospital, he was quite disabled and in urgent need of surgery. At the tertiary hospital, this would cost Rs250,000/- (about US\$ 5,000), to be found and paid out before surgery could take place. Velu is a poor man, with a family. He is currently unable to work, and this sum was far beyond his capacity to pay. The family eventually managed to put together Rs10,000/-; and further sums were collected from the government-run Chief Minister's Fund, from philanthropic organizations, and from staff and other donors. But they were still almost Rs75,000/- short of the target. They approached the thoracic department at the main hospital, offering to pay the sum they had collected. But heart surgery is extremely expensive, and this department has a long line of people needing support. Sadly, there will always be people who have to be turned down. It was beginning to look as if Velu would be dead before the required sum could be collected.

However, the staff would not give up. A successful operation would save a whole family from destitution, and enable Velu himself to

return to being a functioning, contributing member of society. So finally, they approached the Development Office at the main hospital, one of whose tasks is to channel donor funds into useful or needy activities. They had their monthly meeting, and the answer – to everyone’s joy - was yes, they would contribute the required balance of Rs75,000/-, and more if it became necessary. That evening, there was great rejoicing among staff and patients at the urban health centre. A month later, Velu had his operation and is doing well. Soon he will be back with his family and (God willing) back also at working and earning money.

QUESTIONS

1. How can a community or family bear the cost of tertiary care for a poor person?
2. Why is tertiary care so costly? Does cutting cost necessarily mean there is loss of quality?
3. What could be the clinical and social criteria if choices have to be made in allocating limited resources for subsidized high technology treatment? Are we willing to be flexible when needs don’t fit our ‘criteria’?
4. Can tertiary care be free, at the point of delivery, for all who need it? What considerations affect your answer to this question?
5. What does ‘best practice’ mean if it is out of the reach of those who need it?



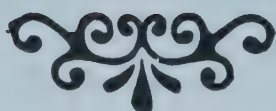
Let me not pray to be sheltered from dangers, but to be
fearless in facing them.

Let me not beg for the stilling of my pain, but for the heart
to conquer it.

Let me not crave in anxious fear to be saved, but hope for
the patience to win my freedom.

Grant me that I may not be a coward, feeling Your mercy
in my success alone; but let me find the grasp of your
hand in my failure.

Rabindranath Tagore



2.8 Ranjit: Death in the community

It is hard to watch young people die, not just because of the sadness for a life cut short, but because early death - for many practitioners - counts as a failure for curative medicine. For religious people, the death of a nineteen-year-old breadwinner may raise questions about God, and about why God allows such things to happen. For all of us, it challenges us to ask questions about life itself and how we understand it.

But looked at another way, death can be an opportunity for healing. In a people-centred, community-based family medicine programme, the challenge to the outreach team is not just to attend to the pain, the fear and the physical deterioration of the dying person, but also, often, to the urgent need for reconciled relationships within families and communities. In addition, the urban health centre has close links with the palliative care department, which cares for dying people in their homes, offering support to families and the resources that make them better able to cope, both before and after the person's death. This case study is closely linked to the one that follows it. For Ranjit's death was not, in fact, the end. Case Study 2.9 tells the story of the series of life-giving events that took place after the boy's death, and as a direct result of it.

Ranjit lived in the Old Town area of Vellore. His alcoholic father died when he was nineteen, leaving him to look after his mother, his younger sister and his two younger brothers. Young though he was, Ranjit became the 'man of the family': the breadwinner who worked and brought home the money. He helped his mother and encouraged his brothers to continue schooling. Concerned for his

sister, he arranged a marriage for her with an older uncle, hoping that the uncle would take on some of the burden of looking after the bereaved family. But this did not please the sister, who eloped with a young man of her own age and choosing.

Hurt and furious, Ranjit disowned her. He struggled on, trying to cope, but hindered by increasingly serious abdominal pains. Eventually, he sought help from the urban health centre, whose staff made regular visits to the Old Town area where he lived. The doctors could not find anything seriously wrong, but they decided to get a second opinion from the consultant surgeons who came to the unit. The surgeons could find nothing either but when the symptoms became more severe they decided on an exploratory operation. Finding nothing wrong in the abdomen, they removed a small lymph node which turned out, on biopsy, to be non-specific. But the young man was still in pain. When he started bleeding from the rectum, he came rushing back to the health centre. There was obviously something very wrong. Taken to the tertiary hospital again, a tumour was found in his colon, with widespread secondaries: extremely unusual in a 22-year-old man anywhere in the world. Beside himself with fear and anger, Ranjit tore up his hospital notes and took himself home. "You have ruined my life!" he shouted.

But in the end, the tumour got bigger, obstructed the bowel, and he had to come back for the final indignity (as he saw it): that is, the fitting of a colostomy bag. Realising that there was little else they could offer, his surgeons referred him to the palliative care unit, where doctors and other staff worked patiently with him to help him come to terms with what was happening to him. They kept in touch with him after discharge from the hospital through

their follow up home visit programme in collaboration with the health centre team. With the help of other family members, they managed to persuade Ranjit to make peace with his sister, and she and her husband and baby son came home and were able to care for him. The health centre team, along with the palliative care team and his own family, made life as comfortable as possible for him, took him out for drives, visited, and got cushions or a mattress to ease discomfort. They adjusted his medicines when the pain became unbearable and were his friends in this difficult final period of his life. Eventually, Ranjit died, having made peace with himself and with the world.

QUESTIONS

1. How does a health care worker deal with the problem of a missed diagnosis?
2. What is the responsibility of the health care worker when the illness is no longer curable and the patient is dying?
3. What are common responses to bad news?
4. Can reconciliation and acceptance be forced? How can we accompany a person on this journey?
5. What is the difference between 'healing' and 'cure'? What happened to Ranjit? Does this have wider implications for others in his family and neighbourhood?
6. What resources exist in a community to deal with terminal illness, dying and death?



I know that this life, missing its ripeness in love, is not
altogether lost.

I know that the flowers that fade in the dawn, the streams
that strayed in the desert are not altogether lost.

I know that whatever lags behind, in this life laden with
slowness, is not altogether lost.

I know that my dreams that are still unfulfilled, and my
melodies still unstruck, are clinging to Your lute strings,
and they are not altogether lost.

Rabindranath Tagore



2.9 Ranjit: Ripples of life

Ranjit's story is told in Case Study 2.8 in this collection. As a nineteen-year-old from a slum, his death from cancer is a story in itself, along with the way his care-givers and family dealt with his illness and dying. But in Ranjit's case, death was not the end. His illness sparked a series of events in his community, and later in neighbouring communities, that were as unexpected as they were life enhancing. For the urban health centre, these events became possible because they had eyes and ears in the community, and the presence of trained, effective volunteers. Combined with an un-bureaucratic, can-do approach to problems, this meant that they were flexible enough to respond quickly and creatively to challenges; and this has resulted in new patterns of community engagement and the development of a whole new level of leadership within their work. Building on existing layers of friendship and of partnership with organizations in the communities, these initiatives have become the inspiration for a much bigger programme that has implications across the city. The ripples of life that spread out from this one death have enriched and will continue to enrich people who have never heard of Ranjit, in ways that he himself would have found incredible.

Ranjit had many friends, young men like himself, many of them members of the 'Sexy Guys' cricket team of which he was a member. They were shocked and frightened by the experience of watching Ranjit die. Why did he get cancer? Would *they* get cancer, too? All of them had experimented with alcohol, tobacco, drugs and sex: was that what had done it? They approached the Old

Town area volunteer, Mary, painting a picture of lifestyles that were, she says, ‘way beyond my imagination’. Shocked but prudent, she approached the staff of the health centre, who offered to meet with the young men.

Thirty five young men from different cricket ‘clubs’ turned up with Mary and her husband to meet with the team. It was soon evident that drugs and sex were more on the boys’ minds than cancer. Over a number of sessions, their questions were answered: the first seriously informative health education most of them had ever had. When the sessions were over, some of them stayed, saying they had realised over these weeks that life could be different, and they wanted to know more.

And so the Life Skills Programme was born: a course of six sessions designed to help young men to develop skills for life in terms of health, the management of time and money, communication, interpersonal relationships, believing in oneself, and the importance of setting goals for their own lives. As it went on, they found themselves wanting to do something not just for themselves but for their own communities.

Before long, the girls in the area decided that they wanted something similar. ‘What about us?’ they asked. Like the boys, the girls who took part in this first life skills course found that they too had become more aware of the needs of their own community, and more confident that they had the capacity to help. Starting with a half-day camp for the elderly, they went on to organize a young mother’s group, meeting once a month to address issues of health care in families. Aware of the isolation, helplessness and chronic illness suffered by many elderly people

in their environment, they helped to organize a clinic for the elderly and people with disabilities along with the team from the health centre.

This story does not end yet. Hearing about what was happening, the headmaster of the middle school contacted the urban health centre and said: “Come and do life skills work with our children”. The success of this programme led in turn to the setting up of a regular programme of working with schools. When the city’s Head of Education learned what they were doing, he suggested that the health centre should run its life skills programme with thirteen middle schools in Vellore City. As a result, a school health education programme with three modules (life skills, health, and accident prevention) has been initiated in these government and government-aided schools.

QUESTIONS

1. How can a tragedy or a critical incident be a source of introspection and new growth in ourselves? In communities? What are the possible barriers and facilitators to the process?
2. What attitudes in health professionals can foster change in people who struggle with addictions or other harmful practices? Is moralizing, judgementalism or insensitive health education useful in bringing about long term change?
3. What was it about the health centre, its staff and its ways of working that enabled the team to facilitate this process? What was it about their relationship with the community that made it possible? Would this be equally possible in a rural setting?

4. What might stop health workers or health institutions responding to opportunities to develop partnerships for change with individuals or communities?
5. Whose responsibility is the health of any individual or community?
6. What is the role of the youth in health promotion in communities?
7. What would be priorities in teaching life skills to youth?
8. What factors enabled the 'ripples of life' that spread and are still spreading from Ranjit's death to so many in the community?

Part Three

THE CENTRALITY OF LIFE



To sacrifice something is to make it holy by giving it
away for love.

Frederick Buechner
Wishful thinking: A Seeker's A B C.



THE CENTRALITY OF LIFE

We have tried to give you a flavour of the work that is done at the LCECU, the Low Cost Effective Care Unit of the Christian Medical College Vellore. Like every other health care facility, ours is to some extent, unique. It is attached to a large tertiary institution. It has an exceptionally strong commitment to the teaching of medical students, nurses and other health professionals. It has fewer financial constraints than some small community based hospitals. However, the context in which it works is representative of many urban situations in the developing world today, particularly in India; and we believe that in putting together these stories from our own context, we have something that is worth sharing with others.

For every story in these pages, there are a hundred others, taken from our own work, which we could have used. We have introduced these particular people to you so that you, the reader, may understand better the context within which we work and the outcomes we hope to achieve. For these men, women and children are to some extent representatives of the health care challenges faced in any urban situation in India at the beginning of the 21st century. At the same time, each one is also an individual; each has his or her own hopes and fears, woes and dreams, joys and sorrow. Each of them is a named person in his or her own right, the centre of a network of relationships that is unique to him and her. He or she is not defined by respiratory disease or diabetes, disability or TB, mental illness or the need for immunisation or antenatal care. In a people-centred, community-orientated programme, each one is defined by their capacity for life, for building community and for hope in the future: whatever it may hold.

It is on this awareness that our vision of primary health care and family medicine is based. The road is not easy. In addressing the 'urban challenge', we are often forced to our knees by apparent resource constraints and societal fragmentation. And yet it is here, at the very roots of the situation, that we are finally confronted with the strength, the continuity and the centrality of life.

Giving

Then said a rich man, "Speak to us of Giving".

And he answered:

You give but little when you give of your possessions.

It is when you give of yourself that you truly give.

For what are your possessions but things you keep and guard for fear you may need them tomorrow?

And tomorrow, what shall tomorrow bring to the overprudent dog burying bones in the trackless sand as he follows the pilgrims to the holy city?

And what is fear of need but need itself?

Is not dread of thirst when your well is full, thirst that is unquenchable?

There are those who give little of the much which they have and they give it for recognition and their hidden desire makes their gifts unwholesome.

And there are those who have little and give it all. These are the believers in life and the bounty of life, and their coffer is never empty.

There are those who give with joy, and that joy is their reward.

And there are those who give with pain, and that pain is their baptism.

And there are those who give and know not pain in giving, nor do they seek joy, nor give with mindfulness of virtue; They give as in yonder valley the myrtle breathes its fragrance into space.

Through the hands of such as these God speaks, and from behind their eyes He smiles upon the earth.

It is well to give when asked, but it is better to give unasked, through understanding;

And to the open-handed the search for one who shall receive
is joy greater than giving

And is there aught you would withhold? All you have shall
some day be given;

Therefore give now, that the season of giving may be yours
and not your inheritors'.

You often say, "I would give, but only to the deserving".

The trees in your orchard say not so, nor the flocks in your
pasture.

They give that they may live, for to withhold is to perish.

Surely he who is worthy to receive his days and his nights
is worthy of all else from you.

And he who has deserved to drink from the ocean of life
deserves to fill his cup from your little stream.

And what desert greater shall there be than that which lies
in the courage and the confidence, nay the charity, of
receiving?

And who are you that men should rend their bosom and
unveil their pride, that you may see their worth naked and
their pride unabashed?

See first that you yourself deserve to be a giver, and an
instrument of giving.

For in truth it is life that gives unto life - while you, who
deem yourself a giver, are but a witness.

And you receivers - and you are all receivers - assume no
weight of gratitude, lest you lay a yoke upon yourself and
upon him who gives.

Rather rise together with the giver on his gifts as on wings;

For to be over mindful of your debt, is to doubt his generosity
who has the free-hearted earth for mother, and God for
father.



Khalil Gibran
The Prophet



LIFE

The temptation is always to reduce it to size. A bowl of cherries. A rat race. Amino acids. Even to call it *a* mystery smacks of reductionism. It is *the* mystery.

As far as anybody seems to know, the vast majority of things in the universe do not have whatever life is. Sticks, stones, stars, space-they simply *are*. A few things *are* and are somehow alive to it. They have broken through into Something, or Something has broken through into them. Even a jellyfish, a butternut squash. They're in it with us. We're all in it together, or it in us. Life is *it*. Life is *with*.

After lecturing learnedly on miracles, a great theologian was asked to give a specific example of one. "There is only one miracle", he answered. "It is life".

Have you wept at anything during the past year?

Has your heart beat faster at the sight of young beauty?

Have you thought seriously about the fact that someday you are going to die?

More often than not, do you really *listen* when people are speaking to you instead of just waiting for your turn to speak?

Is there anybody you know in whose place, if one of you had to suffer great pain, you would volunteer yourself?

If your answer to all or most of these questions is No, the chances are that you're dead.

Frederick Buechner
Wishful thinking: A Seeker's A B C.



'It is not just the causes of disease and death that need to be addressed: it is also major questions about what constitutes health and enhances life. New visions of what is possible demand approaches to health care that are flexible, responsive, people-centred, and based on new patterns of collaboration, networking and leadership. In the light of these challenges, LCECU today has developed its distinctive vision, its philosophy, and a way of working that chimes with the forces of life that exist within the community'.

Extract from the introduction

